

# MY VISIT. OUR PLAN.

PRIMARY BILIARY CHOLANGITIS

WORKBOOK

Tools for today's  
appointment

FALL 2025

STAY ON TRACK:  
**RECORD YOUR  
SYMPTOMS**

page 5



COMPLIMENTARY COPY  
**TAKE ONE HOME**



SCAN ME

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camera to activate  
the QR code.



# PATIENT’S GOALS

## WHAT I’M WORKING TOWARD.

Use this list to keep tabs on your short-term and long-term disease management goals. For example, short-term goals may include getting up-to-date on your vaccines for hepatitis A and B, pneumonia, flu, and COVID; adding more vitamin A, D, E, and K foods as well as anti-inflammatory foods to your diet; and avoiding alcohol. A longer-term goal could be fewer hours a day with fatigue or itching. Write down your goals here:

GOAL	✓/x
1.	
2.	
3.	
4.	
5.	
6.	

Scan or copy this spread before you fill it in to use for two or three months

PORTRA/VIA GETTY IMAGES



# DOCTOR'S RECOMMENDATIONS

## TREATMENT GUIDELINES FROM YOUR MEDICAL TEAM.

The goals of treatment are to reduce inflammation in your liver (to improve its function) and reduce primary biliary cholangitis symptoms like fatigue and itching (to improve your quality of life). Your doctor may have targets like a lower alkaline phosphatase level as they monitor your disease management. Record your doctor's specific goals for you here:

GOAL	✓/x
1.	
2.	
3.	
4.	
5.	
6.	



CHONG KEE SIONG/VIA GETTY IMAGES

# TAKE A MINUTE

PAUSE AND ASK YOURSELF HOW YOU'RE FEELING ABOUT YOUR PBC AND WHAT YOU MAY NEED.

A corkboard with a light wood frame contains six sticky notes, each with a colored header and a white body for writing. The notes are arranged in a 3x2 grid and are pinned with colorful pushpins. Each note has three dotted lines for writing.

- Top Left (Blue header, green pin):** Today I feel ...
- Top Right (Green header, blue pin):** Right now, my body needs ...
- Middle Left (Green header, pink pin):** I can help myself feel better by ...
- Middle Right (Pink header, green pin):** I plan to ...
- Bottom Left (Pink header, blue pin):** I get a boost of energy when I ...
- Bottom Right (Blue header, pink pin):** I'm grateful for ...



# WELLNESS WATCH

**KEEP TRACK OF YOUR PRIMARY BILIARY CHOLANGITIS SYMPTOMS SO YOU CAN GIVE YOUR DOCTOR AN ACCURATE SNAPSHOT OF YOUR CONDITION BETWEEN VISITS—AND BETTER UNDERSTAND HOW YOU'RE DOING YOURSELF.**

Use this chart to record common symptoms and how well treatments work over time. Take note of issues like itching and fatigue plus your current alkaline phosphatase (ALP) levels, diet, and medications you're taking.

CURRENT ALP LEVEL: \_\_\_\_\_

	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
SYMPTOMS							
MEDICATIONS							
DIET							
OTHER							

**SCAN OR COPY THIS PAGE BEFORE YOU FILL IT IN TO USE FOR TWO OR THREE MONTHS**

# UNDERSTANDING AND MANAGING PBC

## TWO EXPERTS HELP YOU PLAN FOR YOUR VISIT WITH YOUR DOCTOR

By Rachel Reiff Ellis

Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer



ADNAN SAID, MD

**P**Primary biliary cholangitis is a chronic condition, which means you'll manage it for the rest of your life. Two PBC experts discuss the questions you'll want to ask your doctor to better understand your disease and how to treat it. Adnan Said, MD, is a gastroenterologist and hepatologist at UW Health in Madison, WI, and Christopher L. Bowlus, MD, is chief of gastroenterology and hepatology at UC Davis Health in Sacramento, CA.

### Q: WHAT ARE THE GOALS OF TREATMENT FOR PBC?

**ADNAN SAID, MD:** The medication we use most commonly for PBC helps maintain bile flow in the liver. Bile is made by your liver and is important for getting rid of toxins and waste products from the body. It also helps in digestion. In PBC, bile isn't excreted well, so it builds up, which can injure your liver. PBC treatment helps to reduce the buildup of bile. It also helps to change that bile into a less toxic bile acid, which doesn't injure the liver as much. It reduces inflammation in the liver. Ultimately, those things can reduce scarring in the liver so that you don't develop cirrhosis—a condition that permanently damages your liver.

### Q: WHAT IS THE MOST COMMON TREATMENT FOR PBC?

**CHRISTOPHER L. BOWLUS, MD:** All patients should first be treated with ursodeoxycholic acid. If after six to 12 months your liver enzyme levels are still not normal, then a second-line treatment should be considered. About 5% of patients can't tolerate this first-line treatment. If this happens for you, then your doctor will move to a second-line agent. There are two categories of second-line agents, FXR agonists and PPAR agonists. It's important to know that FXR agonists can make itching worse while PPAR agonists tend to make it better.

### Q: HOW WILL I KNOW IF THE TREATMENT IS WORKING?

**SAID:** You'll need to see your doctor regularly and get blood tests. One of the most important blood tests is a liver enzyme called alkaline phosphatase. Reduction in alkaline phosphatase is a very good sign that the liver disease is responding to that treatment. If the alkaline phosphatase is not responding, then it may be time to do something else. We also monitor symptoms like itching, fatigue, and other things like potential vitamin deficiencies, vision problems, and pain.





CHRISTOPHER BOWLUS, MD

We consider liver transplant only if there are complications related to cirrhosis, or in very rare cases when itching is extremely severe and cannot be managed medically.

#### Q: WILL I NEED A LIVER TRANSPLANT?

**BOWLUS:** It's important to ask your doctor what your risk of needing a liver transplant is and how much treatment is expected to reduce your risk. Only about 200 liver transplants—less than 5% of the total transplants done each year—are done for PBC, so it is rare.

#### Q: WHAT KINDS OF COMPLICATIONS SHOULD I WATCH FOR WHILE TREATING MY PBC?

**BOWLUS:** Dry eyes and dry mouth are common. If you have these symptoms, consider seeing a rheumatologist for Sjogren's disease. High cholesterol is also common in PBC and can be treated with statins if needed to reduce risks of heart disease. You should get a DEXA scan to screen for osteopenia/osteoporosis, and your thyroid should be checked routinely to screen for thyroid disease.

#### Q: WHAT IS MY PROGNOSIS WITH PBC?

**SAID:** PBC is a chronic condition, but the good news is that it can be controlled with fairly effective and well-tolerated medications. For patients that respond to a usual first-line medication that helps bile flow, liver damage can be halted and even reversed so that patients do well over the long run.



# MY JOURNEY WITH PBC

## FIND THE RIGHT DOCTOR AND PACE YOURSELF

By Jackeline Rojas

Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

In the beginning, I was dealing with a lot of fatigue and a lot of itching on my hands and feet. It happened especially at night, which I didn't understand. I also was dealing with a lot of muscle and joint pain. With those symptoms not being normal for me, I went to see my primary care doctor.

### FINDING ANSWERS

My doctor ran some blood tests and found some elevated liver enzymes. But it took almost a year of continued fatigue and climbing liver enzyme numbers to get my diagnosis of PBC. After I went to see a gastroenterologist, a liver biopsy confirmed I had PBC. Finally, we put a name to what was going on with me. But I still didn't have answers to a lot of questions I had about treatment and how this was going to affect my quality of life.

Later, I started seeing a hepatologist (a liver specialist). He's knowledgeable about PBC and more hands-on. He answered all the questions that I had and clarified things for me. So that was significant. I had a better idea of what I was dealing with and how to move forward.

### TREATMENT MATTERS

I was on a high dose of medication and started losing weight. But after a year, one of my liver enzymes was still higher than my doctor liked. We discussed adding a second medication. That helped and finally brought all my liver enzymes down to a normal range.

I made some dietary changes, and losing the weight was significant because that helped with the fatty liver I was dealing with as well. I lost almost 70 pounds total, so obviously that was beneficial. With the fatigue, it is harder to do. I have to pace myself to get certain things done during the course of the day.

MONTY RAKUSEN/VIA GETTY IMAGES; INSET PHOTOGRAPHY BY JOAL A. CANDELARIO







## STAY IN TOUCH

In addition to my hepatologist, my primary care doctor also stays involved. He follows up with me as far as the dieting and making sure that I continue to progress in my weight loss journey.

Even though my hepatologist deals mainly with the PBC aspect, I've been able to email him about other questions I've had. He's been open about sending referrals, like once when I needed to see a cardiologist. He's focused not just on treating the PBC but also making sure that the patient as a whole is OK. If there's anything that I need, he's there to provide that. So that's a really good thing to have in a provider.

## JACKELINE'S TIPS



- + Trust your instincts.** You know your body. You know when there's something wrong, and you have to stay firm and really advocate for yourself.
- + Look for support groups** available in your area or through social media. Look for a lifeline of community support and people dealing with the same issues.
- + Take care of your mental health.** Get the help that you need because that will be a determining factor in how you move forward with this type of diagnosis.



“ I didn’t feel like other PBC treatments were an option for me. **IQIRVO is helping me meet my treatment goal** of decreasing my ALP levels.\* ”

– **Christine** mom and avid hiker living with PBC

Christine is living with primary biliary cholangitis (PBC) and taking IQIRVO. She was compensated for her time. Individual results may vary. Talk with your doctor about a treatment plan that fits your needs.

\*ALP lowering of IQIRVO was studied in a 52 week trial of 161 patients and lowered ALP in as quickly as 4 weeks, and the effects were sustained over 52 weeks. Some people (15%) achieved a normal ALP level compared to people who took ursodiol alone.

#### INDICATION

##### What is IQIRVO® used for?

IQIRVO is a prescription medicine used to treat primary biliary cholangitis (PBC) in combination with ursodeoxycholic acid (UDCA) in adults who have not responded well to UDCA, or used alone in patients unable to tolerate UDCA. IQIRVO was approved under accelerated approval based on reduction of alkaline phosphatase (ALP). Improvement in survival or prevention of liver decompensation events have not been demonstrated. Continued approval for this indication may be contingent upon verification and description of clinical benefit in confirmatory trial(s). IQIRVO is not recommended for use in people who have symptoms or signs of advanced liver disease. It is not known if taking IQIRVO will improve your chance of survival or prevent liver decompensation. It is not known if IQIRVO is safe and effective in children under 18 years of age.

#### IMPORTANT SAFETY INFORMATION

##### What Warnings should I know about IQIRVO?

IQIRVO can cause muscle problems (myalgia, myopathy, rhabdomyolysis) and muscle pain that can be severe. Treatment with IQIRVO may cause muscle pain or worsen existing pain and can increase the level of an enzyme in your blood called creatine phosphokinase (CPK); both can be a sign of muscle damage. If there is new or worsening muscle pain, your healthcare provider may examine you and perform a blood test. Stop taking IQIRVO and call your healthcare provider right away if you have any of the following signs or symptoms: severe muscle pain, unexplained soreness, unexplained muscle weakness, or dark, reddish urine.

IQIRVO may increase the risk of bone fractures. Tell your healthcare provider about any bone fractures, or if you develop pain, or have changes in your ability to move around.

Please see additional Important Safety Information for IQIRVO on the following pages.



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IQV-US-001898 April 2025

“ When I was first diagnosed with PBC, I struggled with **symptoms like itch that impacted my daily life.** For me, with IQIRVO I feel my PBC symptoms are being controlled.\* ”

– **Jared** animal lover and chef living with PBC

Jared is living with PBC and taking IQIRVO. He was compensated for his time. Individual results may vary. Talk with your doctor about a treatment plan that fits your needs.

\*In the clinical trial, Iqirvo was studied in people who had moderate-severe levels of itch defined as a PBC Worst Itch Numeric Rating Scale (WI-NRS) score greater than or equal to 4. People taking Iqirvo reported on average reduction of 1.93 points in the WI-NRS score, compared to people taking ursodiol alone (average reduction of 1.15 points). People taking IQIRVO reported an average reduction of 2.5 points in the PBC-40 itch score and 4.2 point reduction in the 5-D itch total score compared to people taking ursodiol alone (average reduction of 0.1 points and 1.2 with ursodiol, respectively). Itch was a secondary outcome of the study and **results did not reach statistical significance**. Data should be reviewed with caution. If you have questions about this limitation, your doctor can help explain it further.

#### IMPORTANT SAFETY INFORMATION (continued)

##### What Warnings should I know about IQIRVO?

IQIRVO may cause harm to an unborn baby when taken during pregnancy. Women taking IQIRVO who can become pregnant should use effective birth control during treatment and for 3 weeks after the last dose of IQIRVO. Talk to your healthcare provider about birth control methods that may be right for you. Tell your healthcare provider right away if you become pregnant or think you may be pregnant.

IQIRVO can cause liver problems and abnormal liver blood test results. Your healthcare provider should do tests before starting and during treatment with IQIRVO to check your liver function. Tell your healthcare provider right away if you experience any of the following during treatment with IQIRVO: swelling of your stomach-area (abdomen), yellowing of your skin or whites of your eyes, black, tarry, or bloody stools, mental changes such as confusion, being sleepier than usual or harder to wake up, slurred speech, mood swings, or changes in personality, or coughing up or vomiting blood, or your vomit looks like coffee grounds. If you have severe stomach-area (abdomen) pain, nausea, vomiting, diarrhea, loss of appetite or weight loss, new or worsening fatigue, weakness, fever and chills, light-headedness, or less frequent urination, tell your healthcare provider right away.

Some people taking IQIRVO had allergic reactions, which may include rash, trouble breathing, itching, or swelling of your face, lips, tongue, or throat. If you experience any of these, stop taking IQIRVO, call your healthcare provider right away or go to the nearest hospital emergency room.

IQIRVO can cause blockage of the bile duct and may increase your risk of gallstones. Call your healthcare provider right away if you develop pain in the upper right stomach area or yellowing of the skin.

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**You should not use IQIRVO if you:**

- Have advanced liver disease.
- Are pregnant or plan to become pregnant. IQIRVO can harm your unborn baby. You should not become pregnant during treatment with IQIRVO.
- Are breastfeeding or plan to breastfeed. It is not known if IQIRVO passes into your breast milk. Talk with your healthcare provider about the best way to feed your baby if you take IQIRVO.

**What are the side effects of IQIRVO?**

The most common side effects of IQIRVO include weight gain, diarrhea, stomach pain, nausea, vomiting, joint pain, constipation, muscle pain, bone fractures, gastroesophageal reflux disease (GERD), dry mouth, weight loss, and rash. These are not all of the possible side effects of IQIRVO. Call your doctor for medical advice about side effects.

**What other medications might interact with IQIRVO?**

Tell your healthcare provider about all of the medicines you take, including prescription and over-the-counter medicines, vitamins, and herbal supplements. IQIRVO can affect the way certain medicines work. Certain medicines may affect the way IQIRVO works. If you take a bile acid binding resin, take IQIRVO at least 4 hours before or after you take your bile acid resin.

You are encouraged to report side effects to FDA at 1-800-FDA-1088 or at [www.fda.gov/medwatch](http://www.fda.gov/medwatch). You may also report side effects to Ipsen Biopharmaceuticals, Inc. at 1-855-463-5127. Please see accompanying full Prescribing Information.

**The risk information provided here is not comprehensive. To learn more, talk with your health care provider or pharmacist. The FDA-approved product labeling can be found at [www.IQIRVO.com](http://www.IQIRVO.com).**



– **Cecilia** mom, psychologist & advocate living with PBC

“I’ve been on IQIRVO for 10 months and find **treatment fits my routine** – I take the pill once-daily at a time that **works best for my life**. I also find I am able to manage side effects with my doctor.”



**Hear the impact IQIRVO is making in the lives of people with PBC**

**IQIRVO**  
elafibranor 80 mg tablets

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Cecilia is living with PBC and taking IQIRVO. She was compensated for her time. Individual results may vary. Talk to your doctor about a treatment plan that fits your needs.

**Indication and Important Safety Information**

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If you have severe stomach-area (abdomen) pain, nausea, vomiting, diarrhea, loss of appetite or weight loss, new or worsening fatigue, weakness, fever and chills, light-headedness, or less frequent urination, tell your healthcare provider right away. Some people taking IQIRVO had allergic reactions, which may include rash, trouble breathing, itching, or swelling of your face, lips, tongue, or throat. If you experience any of these, stop taking IQIRVO, call your healthcare provider right away or go to the nearest hospital emergency room.

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elafibranor 80 mg tablets

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# TAKE NOTE

## IF YOU'RE LIVING WITH PBC, YOU CAN LEARN A LOT FROM OTHERS WHO FACE THE SAME CHALLENGES YOU DO

By Sonya Collins | Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

It's a rare disease, but more than 100,000 people in the U.S. have primary biliary cholangitis. Some have been living with the condition for years, and they've picked up a lot of wisdom along the way. Here, some of your PBC peers share what they've learned on their journey. As you read, write down the ways that you can put these lessons into action.

### Words of Wisdom



***"Living with PBC taught me that strength doesn't always look like pushing through—it's also found in resting, asking questions, and letting others in."***

—Lisa Woodcock, diagnosed in 2020



***"You can't do this alone. Join groups and find a community to support you. Adopt a healthy mindset and believe that you can get better."***

—Sharon Speer, diagnosed in 2013, transplanted in 2022



***"Fatigue is real and debilitating, and you are the only one who can feel it. Listen to the symptoms, and understand when your body is telling you it needs rest. You may not like it, and you may have things to do, but you have to be a friend to your body. Your liver is struggling, and you have to help it out. Manage your energy like its gold!"***

—Debbie King, diagnosed in 2019



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***"I've learned to eat around 20 grams of fiber every day. This should come from whole grains, fruits, and vegetables. It feeds and cleans your liver and gives you much-needed energy to get through each day!"***

—Chrissy D. Ellis, diagnosed in 2024



***"Living with PBC, while an overwhelmingly disheartening diagnosis to get, doesn't have to change your identity. I never allow it to become who I am. I always remember that I am stronger than my diagnosis."***

—Erin Grant, diagnosed in 2023



# DON'T DELAY

## ACT NOW TO PROTECT YOUR LIVER FUNCTION AND MORE

By Kendall K. Morgan | Reviewed by Melinda Ratini, DO, MS, WebMD Medical Reviewer

**W**hen you have PBC, it's a good idea to take steps to protect your overall health, with special attention to avoiding extra stress on your liver, says Beshoy T. Yanny, MD, a hepatologist at UCLA Health's Santa Monica Digestive Diseases in California. Yanny advises abstaining from smoking and alcohol. Watch your weight and address any risk factors for metabolic-associated steatotic liver disease (also known as fatty liver), such as obesity, diabetes, or high cholesterol.

"Avoiding unnecessary medications is also something that we try to emphasize in patients with chronic liver conditions such as PBC," Yanny says. "Unnecessary medications such as non-prescribed medications or supplements should be avoided due to scarcity of studies regarding the risks, benefits, drug-to-drug interactions, monitoring parameters, and optimal dosing."

### DIET AND EXERCISE

Yanny suggests limiting the number of carbohydrates and empty calories you eat. Beyond that, he says, studies haven't shown benefits of any particular diet when you have PBC. A healthy diet generally includes plenty of fruits, vegetables, lean proteins, and healthy fats. Exercise is encouraged, but check with your doctor first to address any concerns that may be unrelated to your PBC. Adults should aim for 150 minutes of moderate-intensity aerobic exercise a week plus muscle-strengthening exercises.



"Patients who have severe liver disease, such as liver cirrhosis or fluid buildup in the stomach, should avoid very strenuous exercises and heavy lifting to prevent a hernia," Yanny says. "For those who do not have cirrhosis and have a well-managed primary biliary cholangitis, there aren't restrictions per se for patients to follow in terms of exercise."

### MENTAL HEALTH

Managing your mental health is essential to your well-being with PBC. Ask your doctor about local support groups, or search for one online.

"If a patient has a mental health

concern, such as depression or anxiety, definitely speak with a mental health provider, such as a psychiatrist or psychologist, and discuss those things in detail," Yanny says. "If medications are needed, those can be discussed in conjunction with the liver physician to be sure they don't pose a high risk of liver injury."

Yanny strongly advises keeping up with routine health maintenance. See your primary care doctor for routine visits and screenings. "Continued follow-up in the liver clinic to individualize your care plan and monitor disease progression is strongly recommended," he says.

## A FEW WORDS FROM THE EXPERTS

TOP PRIMARY BILIARY CHOLANGITIS DOCTORS OFFER THEIR INSIGHTS ABOUT THE CURRENT STATE OF PBC CARE AND THEIR OPTIMISM ABOUT YOUR FUTURE

*“Fat in the liver can worsen PBC, so people who are overweight or have obesity, type 2 diabetes, or high cholesterol should focus on healthy nutrition and regular exercise to help keep their liver healthy.”*

—**Monika Sarkar, MD**, associate professor in-residence, Division of Hepatology/Liver Transplant, director, UCSF Women's Liver Program, California

*“This is an exciting time in the field of PBC. There have been tremendous advances in diagnosis and treatment over the past few years. We now have multiple therapies, and once diagnosed and treated, the prognosis is excellent.”*

—**Meena B. Bansal, MD**, professor of medicine, system chief, Division of Liver Diseases, director, MASLD/MASH Center of Excellence, Icahn School of Medicine at Mount Sinai, New York

*“Today, patients with PBC, even those who don't respond to first-line therapy, can look forward to living a normal life with therapies that control the disease and new therapies on the horizon that will reduce the symptoms associated with PBC. Working with your care team, the future is indeed bright.”*

—**Paul Kwo, MD**, professor of medicine and director of hepatology, Stanford University, California

*“The care of patients with primary biliary cholangitis has evolved from symptom management to a precision-based, biomarker-driven approach—highlighting the importance of early diagnosis, individualized risk stratification, and combination therapy to optimize outcomes and delay disease progression.”*

—**Alyson N. Fox, MD**, medical director, Adult Liver Transplant Program, NewYork-Presbyterian/Columbia University Irving Medical Center, New York City

*“Lifestyle changes are essential in the treatment of PBC. Avoiding alcohol and eating a Mediterranean diet may reduce your risk of developing fatty liver disease. Regular exercise may reduce risk of muscle mass loss, known as sarcopenia, and bone loss, known as osteoporosis, which are two common complications in patients with advanced PBC.”*

—**Dian Chiang, MD**, section head of hepatology, Cleveland Clinic, Ohio